Intentionally hastening death by withholding or withdrawing treatment

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Abstract: ZWECK: Diese Arbeit soll empirische Daten zur Absicht des Arztes beim Behandlungsverzicht und -abbruch liefern und deren mögliche Bedeutung für die ethische Debatte diskutieren. METHODIK: Die präsentierten Daten basieren auf EURELD, einem breit angelegten Forschungsprojekt zur Erfassung medizinischer Entscheidungen am Lebensende in sechs europäischen Ländern. Ausgehend von einer fortlaufenden Zufallsstichprobe von Todesfallformularen war der zuständige Arzt anonym schriftlich zu den am Lebensende des Verstorbenen getroffenen Entscheidungen befragt worden. ERGEBNISSE: In allen sechs Ländern zusammengenommen gaben die befragten Ärzte in 45% aller Fälle von Behandlungsverzicht oder -abbruch am Lebensende eine ausdrückliche Absicht zur Beschleunigung des Todeseintrittes an. Höher als der Durchschnitt war dieser Prozentsatz in der Schweiz und in Schweden (52% resp. 51%), tiefer in Dänemark und Belgien (36% resp. 38%), im Mittelfeld lagen Italien und Holland (42% resp. 45%). Insgesamt war der Entscheid zum Verzicht oder Abbruch einer Dialyse oder einer Beatmung besonders häufig mit einer ausdrücklichen Absicht zur Beschleunigung des Todeseintrittes verbunden (57% resp. 54%), der Verzicht oder Abbruch von Krebstherapien besonders selten (34%). SCHLUSSFOLGERUNGEN: Ärztliche Entscheidungen zum Behandlungsverzicht oder -abbruch am Lebensende erfolgen in fast der Hälfte der Fälle mit der ausdrücklichen Absicht einer Beschleunigung des Todeseintrittes. Es findet sich keine klare Assoziation zwischen der ausdrücklichen Absicht zur Beschleunigung des Todeseintrittes und objektiven Merkmalen des jeweiligen Behandlungsabbruches oder -verzichtes wie der Wahrscheinlichkeit resp. dem Ausmaß eines lebensverkürzenden Effekts, der Unmittelbarkeit des Todeseintritts oder der zu erwartenden Belastung durch die mögliche lebenserhaltende Maßnahme. Diese Resultate wecken Zweifel an der Brauchbarkeit des Kriteriums der ärztlichen Absicht bei der moralischen Beurteilung von Entscheidungen zum Behandlungsverzicht und -abbruch

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Intentionally hastening death by withholding or withdrawing treatment

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Absichtliche Beschleunigung des Todeseintritts bei Behandlungsverzicht und -abbruch

Zusammenfassung. *Zweck:* Diese Arbeit soll empirische Daten zur Absicht des Arztes beim Behandlungsverzicht und -abbruch liefern und deren mögliche Bedeutung für die ethische Debatte diskutieren.

Methodik: Die präsentierten Daten basieren auf EURELD, einem breit angelegten Forschungsprojekt zur Erfassung medizinischer Entscheidungen am Lebensende in sechs europäischen Ländern. Ausgehend von einer fortlaufenden Zufallsstichprobe von Todesfallformularen war der zuständige Arzt anonym schriftlich zu den am Lebensende des Verstorbenen getroffenen Entscheidungen befragt worden.

Ergebnisse: In allen sechs Ländern zusammengenommen gaben die befragten Ärzte in 45% aller Fälle von Behandlungsverzicht oder -abbruch am Lebensende eine ausdrückliche Absicht zur Beschleunigung des Todeseintrittes an. Höher als der Durchschnitt war dieser Prozentsatz in der Schweiz und in Schweden (52% resp. 51%), tiefer in Dänemark und Belgien (36% resp. 38%), im Mittelfeld lagen Italien und Holland (42% resp. 45%). Insgesamt war der Entscheid zum Verzicht oder Abbruch einer Dialyse oder einer Beatmung besonders häufig mit einer ausdrücklichen Absicht zur Beschleunigung des Todeseintrittes verbunden (57% resp. 54%), der Verzicht oder Abbruch von Krebstherapien besonders selten (34%).

Schlussfolgerungen: Ärztliche Entscheidungen zum Behandlungsverzicht oder -abbruch am Lebensende erfolgen in fast der Hälfte der Fälle mit der ausdrücklichen Absicht einer Beschleunigung des Todeseintrittes. Es findet sich keine klare Assoziation zwischen der ausdrücklichen Absicht zur Beschleunigung des Todeseintrittes und objektiven Merkmalen des jeweiligen Behandlungsabbruches oder -verzichtes wie der Wahrscheinlichkeit resp. dem Ausmaß eines lebensverkürzenden Effekts, der Unmittelbarkeit des Todeseintritts oder der zu erwartenden Belastung durch die mögliche lebenserhaltende Maßnahme. Diese Resultate wecken Zweifel an der Brauchbarkeit des Kriteriums der ärztlichen Absicht bei der moralischen Beurteilung von Entscheidungen zum Behandlungsverzicht und -abbruch.

Summary. *Purpose:* This study aims to provide empirical data on physicians' intentions in withholding and withdrawing treatment, and to discuss possible implications for the ethical debate.

Basic procedures: The data presented come from EURELD, a large research project designed to investigate medical end-of-life decisions in six European countries. A continuous random sample of death certificates formed the basis for contacting doctors who had attended the deceased; the doctors were asked to complete, strictly anonymously, mail questionnaires on the decisions taken at the end of their patients' lives.

Main findings: In the six countries studied, physicians reported they had the explicit intention of hastening the end of life in 45% of all treatments that were withheld/withdrawn. The highest numbers of cases with an underlying intention of hastening the end of life were found in Switzerland and Sweden (52% and 51%, respectively); the lowest figures came from Denmark and Belgium (36% and 38%). Middle-ranking countries were Italy (42%) and the Netherlands (45%). Overall, dialysis and respiration were comparatively more often forgone with the explicit intent to hasten the end of life (57% and 54%, respectively), whereas a particularly low percentage of cases with such an explicit intention was found for oncotherapy (34%).

Principal conclusions: In almost every second case, a medical decision to withhold or withdraw treatment is taken with the explicit intention of hastening the end of the patient's life. No clear association can be found between the intent to hasten the end of life and features of the treatment forgone that can be determined objectively, such as the likelihood and extent of a life-shortening

effect, the immediacy of death, or the expected burden of any potential life-sustaining measure. The findings of the study challenge the usefulness of doctors' intentions with regard to hastening the end of life as criteria for moral judgements on decisions to withhold or withdraw medical treatment.

Key words: Euthanasia, withholding treatment, double effect, medical ethics, questionnaires.

Introduction

In any medical action with the potential to hasten the end of a patient's life, the doctor's intent is crucial from both the ethical and legal points of view. Depending on whether the doctor merely had to accept the hastened death as an unavoidable but unintentional side effect of the therapy, or whether he/she explicitly intended such acceleration, the administration of a drug with the potential to hasten death is classed as indirect or direct active euthanasia, respectively [1]. The former is usually seen as an acceptable action and is not illegal, whereas the latter would in principle carry a jail sentence in most westernized countries. This juridical approach is based on the so-called doctrine of double effect that comes from Catholic moral theology [2]. The Netherlands and Belgium are the only two countries in the world where the intentional ending of a patient's life can also be legal, provided the act was carried out at the explicit request of the patient.

In recent years a number of empirical studies have been published in several European countries on the occurrence of, and the conditions associated with, indirect and direct active euthanasia [3–5]. The ethical debate has considered these findings in full and discussed them intensely. The result has been a wide range of sometimes diametrically opposed conclusions [2, 6, 7]. Although this debate has focused on active measures such as the administration of opioids and/or sedatives, intentions also play a role in decisions to withhold or withdraw life-sustaining medical treatment. The distinction between direct (intended) and indirect (merely accepted) hastening of death and the doctrine of double effect, is thus also applicable in the context of withholding/withdrawing treatment [2, 8]. However, empirical data on doctors' intentions when withholding and withdrawing treatment are still scarce. Apart from a few general findings presented in the broader context of two nationwide studies on medical end-of-life decisions in Holland and Belgium [4, 9], we are aware of very few reliable data from Europe on this subject.

The aims of this article are to provide a detailed overview of data on doctors' intentions in withholding and withdrawing treatment, drawn from a large empirical study on medical decision-making at the end of life, and to discuss possible implications for the ethical debate.

Methods

The data presented in this study come from EURELD, a large empirical research project designed to investigate medical end-of-life decisions in six European countries. Large random samples of death certificates formed the basis for contacting doctors who had attended the deceased before death, and the doctors were asked to complete a mail questionnaire in a strictly anonymous manner. Approval by a research ethics committee was obtained in each country where this was required: Belgium, Italy, and Sweden, [10]. The detailed methodology and the main findings of the principal categories of medical end-of-life decisions have been published elsewhere [5, 11].

The EURELD investigation was based on a questionnaire that had been used successfully in two earlier Dutch studies and in one in Belgium [4, 6, 12]. An English version of this questionnaire was scrutinized by all the members of the EURELD consortium: medical doctors, epidemiologists, ethicists and sociologists, many of whom had long-standing experience in end-of-life research. Where necessary, phrasing of the questions was adapted to the international focus of the EURELD project. The questionnaire was then translated into the languages of the countries involved. A standardized procedure, including an in-

Table 1. Explicit intention vs simple acceptance of hastening the end of life according to different types of treatment forgone (withheld/withdrawn) in six European countries

	Total treatments forgone in all six countries (n = 9407)		Treatments withheld in all six countries (n = 5612)		Treatments withdrawn in all six countries (n = 3795)	
Type of treatment	Hastening the end of life explicitly intended	Hastening the end of life accepted but not intended	Hastening the end of life explicitly intended	Hastening the end of life accepted but not intended	Hastening the end of life explicitly intended	Hastening the end of life accepted but not intended
Medication	43	57	51	49	38	62
Hydration/Nutrition	49	51	50	50	46	54
Respiration	54	46	49	51	66	34
Oncotherapy	34	66	34	66	34	66
Surgery	44	56	44	56	46	54
Dialysis	57	43	51	49	69	31
General	43	57	43	57	44	56
Total treatments	45	55	48	52	41	59

Data are weighted row percentages, rounded to whole numbers.

Table 2. Explicit intention vs simple acceptance of hastening the end of life according to different types of treatment forgone in each of the six European countries studied

Type of treatment	Treatments forgone in Belgium (n = 1517)		Treatments forgone in Denmark (n = 1111)		Treatments forgone in Italy (n = 233)		Treatments forgone in the Netherlands (n = 3131)		Treatments forgone in Sweden (n = 1094)		Treatments forgone in Switzerland (n = 2321)	
	int.	acc.	int.	acc.	int.	acc.	int.	acc.	int.	acc.	int.	acc.
Medication	36	64	30	70	56	44	46	54	43	57	52	48
Hydration/ Nutrition	43	57	44	56	32	68	45	55	60	40	57	43
Respiration	43	57	60	40	*	*	64	36	58	42	56	44
Oncotherapy	31	69	16	84	*	*	32	68	28	72	41	59
Surgery	28	72	36	64	*	*	45	55	51	49	54	46
Dialysis	54	46	61	39	*	*	60	40	71	29	54	46
General	37	63	39	61	63	37	37	63	46	54	53	47
Total treatments	38	62	36	64	42	58	45	55	51	49	52	48

Data are weighted row percentages, rounded to whole numbers. *int*. Hastening the end of life explicitly intended; *acc*. hastening the end of life accepted but not intended. * Small numbers of cases (fewer than 10 unweighted cases) therefore percentages not calculated.

dependent back-translation by a native English speaker and comparison of this version with the original questionnaire, was used to ensure the accuracy of the translation. Preliminary tests with doctors working in clinical practice were carried out in each participating country to ensure the validity of the questionnaire in the different national settings before the definitive international text was agreed on.

In the definitive version of the EURELD questionnaire, doctors were asked whether they had withheld or withdrawn a treatment taking into account that this would probably or certainly hasten the end of the patient's life. For all affirmative answers, which were classified as non-treatment decisions, an additional question asked whether or not the doctor took the decision with the explicit intention of hastening the end of life. A footnote indicated that "hastening the end of life" included "not prolonging life". The doctor was also asked to specify the treatments which had been withheld or withdrawn.

Results

The response rates for the EURELD questionnaire were 59% in Belgium, 62% in Denmark, 44% in Italy, 75% in the Netherlands, 61% in Sweden and 67% in Switzerland. Information on the doctor's intent was available for 9368 of the total 9407 treatments where the attending physician had taken into account that withholding/withdrawal would probably or certainly have a life-shortening effect.

In the six countries studied, physicians reported they had the explicit intention of hastening death in 45% of all potentially life-prolonging treatments that were withheld/withdrawn (Table 1). The types of treatment forgone with a high intent to hasten death were dialysis (57%) and respiration (54%); a particularly low number of cases with such an explicit intention was found for oncotherapy (34%).

Overall, an explicit intention was more common in withholding (48%) than in withdrawing (41%) treatment, mainly because in the medication group – which accounted for almost half of all treatments forgone [11] – intent to hasten the end of life was clearly more common when a treatment was not started (51%) than when it was stopped later (38%). On the other hand, in the respiration and the dialysis categories, an explicit intention of hastening the end of life was found more often when treatment was withdrawn than when it was withheld.

Regarding the differences between the countries studied, the highest numbers of cases with an underlying intention of hastening death were found in Switzerland and Sweden (52% and 51%, respectively – Table 2); the lowest figures came from Denmark and Belgium (36% and 38%). Middle-ranking countries were Italy (42%) and the Netherlands (45%).

In each of the six countries, decisions to forgo dialysis and respiration were more likely to be taken with an explicit intention of hastening death than a decision to forgo oncotherapy (dialysis – ranging from 54% in Belgium and Switzerland to 71% in Sweden; respiration – ranging from 43% in Belgium to 64% in the Netherlands; oncotherapy – ranging from 16% in Denmark to 41% in Switzerland).

Discussion

This is the first article providing a detailed overview of European doctors' intentions with regard to withholding or withdrawing treatment at the end of their patients' lives.

Comparison with results of earlier studies

Our study's finding that the decision to withhold or withdraw potentially life-prolonging treatment was made with the explicit intention of hastening the end of life in almost half the cases (45%) is in line with results of similar studies carried out earlier in the Netherlands and

Belgium. From the data reported by van der Maas and co-workers, it can be concluded that in the Netherlands in 1990 there was an explicit intent to hasten the end of life in more than one-third of the decisions to forgo life-prolonging treatment [9]. Deliens and co-workers reported on the 16.4% of all deaths in Flanders, Belgium, in 1998 that occurred after withholding or withdrawing potentially life-prolonging treatment: 6.7% were decided on with no intention of hastening death, 3.9% with the additional intention, and 5.8% with the explicit intention of hastening death [4]. Neither of these studies provided any information on intention related to the type of treatment forgone.

Intention of hastening death in different types of treatment forgone

Our study results show higher proportions of explicit intention of hastening the end of life in decisions to forgo dialysis and respiration, and a lower proportion for withholding/withdrawing oncotherapy; remarkably, this was seen in each of the six countries studied, although at different levels. It is difficult to interpret these findings conclusively but certain speculative comments can be made.

One assumption could be that an explicit intention was reported especially in those cases of forgone treatment where the life-shortening effect was not only possible but almost certain. The study provides no direct information on this. However, doctors were asked to indicate by how much a life had been shortened in consequence of the treatment forgone. This showed that the highest percentages of cases with a life-shortening effect of more than one month were for dialysis and oncotherapy [11], thus there is no obvious relationship between the extent to which life was shortened and the reported intention of hastening death. In addition to the likelihood and the extent of a death-hastening effect, one could assume the immediacy of death as a consequence of the decision to withhold or withdraw treatment to be associated with an explicit intention. Although it is not easy to relate "immediacy of death" to the categories of treatment forgone that we have used, the effect of forgoing dialysis or respiration might be viewed as particularly immediate, especially when an established treatment is stopped. A possible association with "immediacy of death" could explain the high percentages of explicit intention in the respiration and the dialysis categories, in particular when these treatments are withdrawn.

On the other hand, the more adverse effects associated with a treatment, the more likely it seems that the main intent of the decision to forgo this treatment was to spare the patient the burden of treatment (and not primarily to hasten the end of life). The assumption that many oncotherapies today still have serious adverse effects could partly explain the low percentage of explicit intention in this category.

With regard to the differences in explicit intention from country to country, we did not find any conclusive explanation for the fact that doctors in Switzerland and Sweden reported an explicit intent to hasten death more often than doctors in Denmark and Belgium. It might be expected that the number of non-treatment decisions when death was deliberately hastened would be higher in those countries where the intentional hastening of death is more common when administering drugs to patients at the end of life. However, our data do not support this hypothesis. Among the EURELD countries, the intentional administration of lethal drugs is comparatively common in the Netherlands and Belgium [5] – both countries in which the proportion of intentional hastening of death in non-treatment decisions was not especially high.

Intent to hasten death as a normative criterion in the end-of-life debate

According to traditional Catholic moral theology, it is beyond doubt that not only killing but also intentionally allowing someone to die is an evil act per se and can never be justified, no matter what the circumstances [2, 8]. Some experts hold the view that non-intentionality is an inherent feature of both passive euthanasia and of withholding and withdrawing treatment, so that there can be no such thing as "intentionally allowing to die" [7, 13]. Whereas the former is clearly a normative judgement, the latter appears to be more of a factual belief. Neither statement seems ever to have been discussed in the context of empirical findings.

The data presented in this paper clearly show that the view that withholding or withdrawing treatment means allowing patients to die, even though not intending them to do so, is untenable from an empirical point of view. In fact, almost every second medical decision to withhold or withdraw treatment at the end of life is taken with the explicit intention of hastening death.

Whether this finding has any implications for considering that intentionally allowing someone to die is a morally justifiable action poses a different question. In principle, empirical data cannot answer the question of whether a normative judgement is right or wrong. However, considering that non-treatment decisions preceded between 6% (Italy) and 41% (Switzerland) of all deaths in the EURELD countries [11], the conclusion that intentionally allowing a hastened death is always morally wrong would mean disapproval of a considerable number of medical decisions at the end of life. What we can say is that in the context of withholding and withdrawing treatment there is great divergence between the traditional moral rule and today's medical practice.

This does not necessarily mean that the doctrine of double effect is of no use in separating the acceptable from the unacceptable in medical end-of-life decisions. It has been argued that with active measures (indirect and direct active euthanasia) this doctrine is still absolutely meaningful, whereas the primary consideration with non-treatment decisions/passive euthanasia is the difference between action and omission [14]. Applying the rule of double effect *in combination with* the actions and omissions principle could therefore still serve a useful purpose in the field of medical end-of-life decisions. This is also the legal position in most westernized countries today, except in the Netherlands and Belgium [15]. However, if actively hastening death can be allowed (in indirect euthanasia), and intentionally hastening death can be allowed (in passive euthanasia), the question remains of what is so problematic about their combination [14]. And a few

authors have even challenged the normative relevance of the difference between action and omission [16].

Study limitations

There are several limitations to this type of empirical study, as we have pointed out earlier [5, 11]. Bias invoked by non-response or by considerations of social acceptability cannot be excluded. Another limitation concerns the recollection of doctors who are asked to note down details of a patient who died several weeks/months previously. There are also limitations to a wholly neutral and objective assessment of practices in such a highly controversial area, charged as it is with different, sometimes even opposed, moral values and convictions. Slight modifications in the phrasing of the questions, such as "not prolonging dying" instead of "not prolonging life" might have in some cases been crucial to whether a doctor perceived the question as relating to the decision he/she made. Whereas "hastening the end of life" was used in the EURELD study as the superordinate concept for medical decisions with a possible or certain life-shortening effect, corresponding to the German term "Sterbehilfe", some doctors might have felt that in withholding/withdrawing treatment they intended to avoid prolonging life but not to shorten it [17]. This view is based on the idea that there is a naturally allotted life-span, after which the use of life-saving and life-sustaining measures becomes prolonging life. As the application of this concept might be highly subjective [18], we felt that providing both formulations, as explained in the methods section, was the best solution. Finally, we cannot rule out that individual doctors may have had a different understanding of the word "intention". Validation in this area has proved difficult, as human intention is multilayered, subjective, often ambiguous, and sometimes even contradictory [19].

Conclusions

In almost half the cases, a medical decision to withhold or withdraw treatment is taken with the explicit intention of hastening the end of the patient's life. No clear association can be found between doctors' intentions and features of the treatment forgone that can be determined objectively, such as the likelihood and extent of a death-hastening effect, the immediacy of death, or the expected burden of any potential life-sustaining measure. These findings challenge the usefulness of doctors' intentions with respect to hastening the end of life as criteria for the moral judgement about decisions to withhold or withdraw medical treatment.

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